

The Implications of an Epidemiological Mistake: A Community's Response to a Perceived Excess Cancer Risk

ABSTRACT

Objectives. The response of community residents to a perceived cancer excess may include changes in attitude, health-related behavior, and property values. In 1986, a cancer agency conducted a study of cancer incidence (1979 to 1983) in two suburbs of Edmonton, Alberta, and reported elevations on the order of 25% over expected for most sites. Reanalysis of these data several months later revealed an error. Correction brought the rates into line with Alberta as a whole and with other communities surrounding Edmonton.

Methods. We used public opinion trends and property value trends (during the period of concern) to study the two communities affected by the allegation of increased cancer risk.

Results. A survey of residents found significant differences at the time in health-related behavior and beliefs suggesting increased perception of personal, family, and community risk and modest changes in behavior. Real estate values in one community temporarily lost an average of \$4000, or about 5% of total value, compared with a similar, adjacent housing market.

Conclusions. The perception of an elevated cancer risk, in the absence of a true risk, may have a substantial negative effect on the affected community, both psychologically and economically. (*Am J Public Health*. 1993;83:233-239)

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Introduction

Two suburbs of the Canadian city of Edmonton were affected by a period of uncertainty due to an epidemiological error that resulted in the public announcement of a cancer excess in a study that later proved false. Prior to correction of the error, we studied these communities and a nearby comparison town to identify differences in health attitudes, behavior, and property values that may have been attributable to the labeling effect. The impact of this incident on the communities is of interest both as a cautionary case study and as an indication of the purely psychological implications of a perceived excess risk in the demonstrable absence of a true excess cancer risk.

Case Study

The sequence of events in this episode is described in detail elsewhere.¹ This summary presents only the essential features needed to understand the incident. Residents of two adjacent communities in the province of Alberta, Canada, had been concerned for several years about an apparently elevated rate of cancer among adults in their community. This concern was given some superficial validation by clergy in the area who reported that an unusual number of their pastoral calls had been made to visit church members with cancer. Speculation among residents on the cause for this putative association centered on the concentration of oil refineries in eastern Edmonton near community 1 and petrochemical facilities in community 2. Community 1 is an affluent, recently developed suburban bedroom community with some light industry, located east of Edmonton. Community 2 is an established, also affluent, industrial

community northeast of Edmonton dominated by petrochemical plants, with a more blue-collar and industrial tradition than community 1.

In 1986, the provincial agency responsible for monitoring cancer rates conducted a preliminary study of cancer incidence in the county compared with Alberta as a whole. The agency has, as its chief epidemiological resource, a population-based cancer registry that records all cases of cancer identified in the province as collected from referrals to the two cancer diagnosis and treatment centers, summary reports submitted on a mandatory basis by practitioners, reports from pathologists, and death certificates filed for residents of the province, wherever the deaths may occur.

The study evaluating rates for the two communities was performed by identifying all cancers occurring among county residents from 1979 to 1983 and comparing the number falling in each principal category (by site and type) with what would be expected for a population of the same size and age distribution taken at random from Alberta as a whole. The study determined that the overall cancer rate and many site-specific rates in the communities appeared to be significantly higher than for Alberta as a whole, on the order of 25%.¹ (Several newspaper reports mentioned 44% from

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TABLE 1—Demographic Profile of Survey Respondents

	Community 1, No.	Community 2, No.	Comparison Community 1, No.
Sex of respondent			
Male	51	50	50
Female	49	50	50
Age of respondent			
20–39	50	40	52
40+	50	60	48
Home ownership			
Rent	10	12	12
Own	90	87	88
Duration of residence in home, y*			
<1	8	4	6
1–5	35	30	51
6–10	25	30	14
10+	32	36	29
Duration of residence in town, y**			
<1	6	3	2
1–5	23	16	39
6–10	25	31	14
10+	46	50	44
Education**			
Secondary	49	66	45
Postsecondary	51	34	55
Occupational status***			
Professional	24	12	24
Manager	7	2	10
Blue collar	10	5	9
Farmer	0	8	1
Unemployed	0	1	1
Retired	3	15	11
Work at chemical plant	6	13	1

* $P < .03$; ** $P < .01$; *** $P < .001$.

*The original list of occupations included 14 items; these are selected entries.

an earlier estimate.) This excess was observed for most major sites and types of cancer in both men and women, but the elevated rates were not statistically significant (at $P < .05$) for individual sites except for cancer of the intestine (and rectum) among men and for ovary (and female genitalia) and bladder (and kidney) cancer among women. We have chosen not to present a table of these findings in this report, because they are now known to be erroneous. This table has been presented elsewhere.¹

The results conveyed an impression of a general, across-the-board elevation upon which were superimposed chance variations. The elevations reported would have been unusually consistent for cancers not thought to be associated with chemical exposure, and the epidemiologic patterns for the site did not fit the usual

patterns observed for occupational or environmental causes of cancer. Those cancers most characteristically associated with chemical exposures (lung, bladder, skin, leukemia) were *not* reported to be strongly elevated among men or women.

The findings were summarized in a draft document dated January 19, 1987, that was widely circulated and publicized in the press, although it was never intended to be a definitive scientific report. There is speculation that it leaked to news media from a high government office. The report noted that statistical artifacts were possible and explicitly mentioned population estimates as one source of possible error. It also emphasized that a thorough search for other explanations must be conducted before attributing the excess to environmental factors. Despite these caveats, the local media reported the story in

graphic terms over the next several months. One front-page headline read: "Cancer risk revealed: [community 1] 50% more prone to some diseases."

In response to this unexpected issue, the provincial cabinet minister responsible for community and occupational health requested a reanalysis covering a longer time period to be undertaken by the agency in partnership with an external, academic unit to provide validation in public communications. A task force of experts and community residents was also convened to discuss the implications. At all times, the agency cooperated fully and responsibly under often difficult circumstances of adverse public opinion.

A reanalysis of these data by the agency responsible in partnership with the Occupational Health Program at the University of Alberta revealed that the combined population figure used to calculate the combined cancer rates for community 1 (population 52 000) and community 2 (population 12 000) was in error. The figure for community 2 was erroneously assumed to be included in the figure used for community 1. In reality, the two never had been amalgamated politically or for census purposes. The clerical staff using the tables were unaware that community 2 was an independent city and not part of the adjacent county. Omission of the population of community 2 from the "denominator" (population at risk) resulted in an underestimate of population of 12 169, or 19.09% of the total, enough to account for the excess observed at all sites combined. In other words, leaving out approximately 19% of the population base inflated all incidence ratios by 23% (not allowing for age adjustment). The error is perhaps more understandable when one considers that the reporting of population figures by Statistics Canada does not correspond to local postal or special service districts and was documented in a confusing set of tables in which independent cities were not entered near the adjacent counties. Correction of the mistake brought the calculated rates into line with those for Alberta as a whole and with those for other communities in Census District 11, the ring of suburban communities surrounding Edmonton.² The sole apparent excess appears to be bladder (and kidney) cancer among women, but a closer look at the individual case mix has made it clear that there is no convincing common association even within this small group.

The reanalysis was audited by our academic unit, including a review of all calculations. We jointly certified the reanal-

ysis as valid in a letter to the minister responsible for community and occupational health. The accurate findings were released at a press conference on May 28, 1987. The press conference was extensively covered in the local media, with headlines such as "Cancer figures faulty" and "Cancer study had math error, [minister] says."

Methods

Historical Reconstruction

In order to fill in the gaps of the chronology and to obtain further background information on community attitudes before the media announcement of the putative cancer excess, we obtained the services of a free-lance investigative reporter and former columnist for the newspaper serving community 1. She was authorized to interview residents and local government officials to reconstruct the local history of the incident but did so only after completion of the community surveys.

Community Surveys

Given the unique opportunity to examine the effect of "labeling" a community as at excess risk of cancer in the absence of a true risk, we quickly organized a telephone survey of community residents. The survey was conducted during 1 week in April of 1988, after the error in calculation was identified and the true results were known but before the press conference at which the findings were publicly released. At the time, there had been no publicized developments in the issue for some months, and the findings of the reanalysis were not known outside of the responsible agency, the University of Alberta, the responsible provincial government agency, and Alberta Community and Occupational Health.

Trained professional telephone interviewers in the service of the Population Research Laboratory of the University of Alberta called a randomly generated sequence of telephone listings in prefixes serving community 1 and community 2. The survey was also conducted in a locally relevant community (comparison community 1), another suburb of Edmonton (population 32 000), known to be demographically similar to community 1 and as well established historically as community 2. The respondents were screened for age (over 21) at the time the interview was conducted. For each community, calling continued until 100 respondents were ob-

Survey Items/Response	Community 1, No.	Community 2, No.	Comparison Community 1, No.	P
Environment becoming increasingly polluted; chemicals are affecting health				
Agree	86	86	91	NS
Disagree	11	12	9	
Don't know	3	0	2	
Community is safe with respect to chemical hazards				
Agree	51	44	81	<.001
Disagree	38	56	13	
Don't know	11	0	6	
Neighbors have experienced health problems				
Agree	12	31	6	<.001
Disagree	56	49	82	
Don't know	32	20	12	
Respondent's family is at increased risk for health problems because of environment				
Agree	29	49	4	<.001
Disagree	67	49	93	
Don't know	4	2	3	
Respondent and family have elevated risk for health problems				
Agree	18	43	1	<.001
Disagree	76	56	94	
Don't know	6	1	5	
Local and provincial public health authorities are adequately protecting health from chemical hazards				
Agree	45	46	48	NS
Disagree	40	47	36	
Don't know	15	7	16	

Note. NS = not significant.

tained, 50 of each sex. This protocol was similar to standard public opinion survey methods used by the Population Research Laboratory.

The survey instrument consisted of 19 major items intended to provide information on attitudes toward and perceptions of personal and community risk, health-related behavior, and property. Participants were not informed of the purpose of the study until the end of the telephone interview. They were then told that subsequent analysis had revealed that their community was not at excess risk for cancer and were reassured that the survey did not imply that their community was at risk.

Property Values

We contacted the Edmonton Real Estate Board to obtain real estate sales figures

for community 1 and an appropriate real estate market sharing similar characteristics (comparison community 2). Recognizing that averages could be misleading because of changes in the mix of houses sold in a given month, we selected a single category of housing common in community 1 to be a standard for comparison: bungalow-style single-family dwellings with six rooms, including three bedrooms. Among the real estate areas available for comparison, several had opened housing tracts during the period of interest or were in the midst of other developments likely to affect the housing market locally. Among those that had not done so, the area most similar to community 1 in distribution of type of housing and price was the southeast district of the city of Edmonton, which is adjacent to but separated from community 1 by a

TABLE 3—Perceptions of Health Status among Survey Respondents

Survey Items/Response	Community 1, No.	Community 2, No.	Comparison Community 1, No.	P
Respondent personally has experienced health problem thought to result from chemical exposure ^a				
Yes	11	17	5	NS
No	88	83	94	
Don't know	1	0	1	
Member of respondent's family has experienced health problem thought to result from chemical exposure ^b				
Yes	12	25	8	<.01
No	87	74	92	
Don't know	1	1	0	
Respondent or member of family is sick more often than others same age				
Yes	3	8	3	NS
No	96	88	96	
Don't know	1	4	1	
Residents of community experience higher rates of chronic disease than elsewhere				
Yes	12	31	6	<.001
No	70	48	84	
Don't know	18	21	10	
The chronic diseases allegedly being experienced at higher rates				
Cancer				
Yes	30	36	4	<.001
No	55	47	83	
Don't know	14	17	13	
Birth defects				
Yes	4	8	0	<.001
No	79	62	87	
Don't know	16	30	13	
Allergies				
Yes	37	46	13	<.001
No	50	42	72	
Don't know	13	12	15	
Heart disease				
Yes	3	5	1	NS
No	79	69	85	
Don't know	17	26	14	
Problems involving mental health				
Yes	9	10	4	NS
No	77	70	83	
Don't know	14	20	13	

Note. NS = not significant.

^a13 illnesses reported by respondents from both affected communities: allergies, respiratory symptoms, sinusitis, "sore eyes," cancer (1 case from community 2) ($P = .08$); 15 illnesses reported by respondents from comparison community: same as for both communities (including cancer case) plus headache, visual changes, "poor immune system."

^b20 illnesses reported by respondents from both affected communities: allergies, respiratory problems, headaches, cancer (1 case for community 1, 3 cases for community 2); 25 illnesses reported by respondents from comparison community 1: same as for both communities (including 4 cancer cases) plus gastrointestinal complaints, hearing changes, "stress," sinusitis, sore throat.

greenbelt-like corridor. This was chosen as comparison community 2 for examining real estate values. We collected data on sales prices for the standard comparison dwelling from 1985 to 1989, flanking the period of interest. We did not compare prices for homes in community 2 because of the absence of an appropriate comparison community sharing housing market characteristics.

Sales price data were smoothed using a 4-month moving average, and a regression equation was run with sales price difference between the two communities being the dependent variable and the independent variables being a trend variable and a categorical variable with a value of 0 for the months outside the study months and 1 for the 5 study months.

Results

Table 1 compares the demographic profile of respondents from community 1, community 2, and comparison community 1. Residents of community 2 were significantly more likely to have lived in the community and in the same home than residents of the other two communities; also, they were less likely to be educated beyond high school and more likely to be retired or to work at a chemical plant. Response patterns were consistent between male and female residents of the same communities. Because the response patterns were so similar, they are not separately tabulated.

Table 2 compares opinions regarding general risk. Residents of the affected communities, especially community 2, showed evidence of greatly increased concern for the safety of their communities and a perception of increased risk for health problems. They also disagreed only slightly more often in response to a question regarding whether public health authorities were adequately protecting them from chemical hazards, a difference that did not achieve statistical significance.

Table 3 compares self-perceptions of health status and perceptions for family members and neighbors. Residents of the affected communities did not appear to perceive themselves as experiencing health problems related to chemical exposure but did report that other family members and other residents in the community had been affected, particularly with cancer, birth defects, and allergies. However, an overwhelming majority in each community reported that they or

their family members were sick no more often than others of the same age.

Table 4 compares beliefs related to health and recent changes in health-related behavior. There was no significant difference in responses to a series of questions emphasizing belief in prevention and personal control over health risks. Respondents of the affected communities did not consistently report that they had not changed their own health-related behavior in response to the situation. Community 1 did so respond, but residents of community 2 did not. More detailed questions revealed that a significantly greater number of respondents in community 1 had changed their diets and had engaged in a variety of other health-related behaviors (in response to a question item that referred to "habits") but that the residents of comparison community 1 had done likewise and in greater numbers with respect to diet.

Table 5 presents the responses to questions related to residence and property values. Residents of the two affected communities were more likely to have reported that they had considered moving away and, although this item did not achieve statistical significance, that they had pursued selling their home. However, residents of community 1 did not report that they believed that the value of their property had changed more often than residents of community 2. Community 2 is considered by realtors to be an altogether different housing market that does not move in parallel with the other two and that has been volatile in recent years, in part reflecting the vicissitudes of the petrochemical industry.

Real Estate Values

Figure 1 shows the pattern of real estate values from 1985 to 1989 in community 1 and comparison community 2. The two track closely in parallel until approximately September 1986, when they begin to diverge. Excepting an atypical "blip" in housing prices in southeast Edmonton in December 1986, there is a steadily widening divergence as prices in southeast Edmonton continue the almost monotonic rise of the previous 2 years and prices in town drop to a nadir in April 1987. Thereafter, the prices rapidly rise, returning to levels close to those of southeast Edmonton by August 1987. Referring to our regression equation, the trend variable was not significant, but the categorical variable was significant ($P < .001$). Its value indicated that the perceived risk was associated with a re-

Survey Items/Response	Community 1, No.	Community 2, No.	Comparison Community 1, No.	P
Health-Related Beliefs				
Individuals can change own health risks				
Agree	97	92	95	NS
Disagree	3	7	4	
Don't know	0	1	1	
Health is determined by environmental factors (where one lives)				
Agree	43	45	42	NS
Disagree	52	50	55	
Don't know	5	5	3	
Individuals have personal control over their health except for accidents				
Agree	60	56	65	NS
Disagree	37	41	34	
Don't know	3	3	1	
Changes in Health-Related Behavior				
Respondent has changed own health-related behavior ^a				
Yes	26	14	17	NS
No	73	83	81	
Don't know	0	3	2	
Respondent has changed own diet				
Yes	36	25	44	<.02
No	64	75	56	
Don't know	0	0	0	
Respondent has changed own health-related habits ^b				
Yes	51	29	35	<.02
No	49	70	65	
Don't know	0	0	0	

Note. NS = not significant.
^a1 nonrespondent.
^bReported changes in habits by respondents in both affected communities: increased exercise, change in diet, quit smoking, change water supply, avoid aerosol cans, quit drinking, control weight, take vitamins; reported changes in habits by respondents in comparison community 1: increased exercise, change in diet, quit smoking, change water supply, "conservative" life-style.

duction in housing prices of roughly \$4000 (about 5% of the house value).

The timing of trends in housing prices in the town correlates closely with the chronology of major events in the false cancer issue. The widest differential in housing prices in April 1987 coincided with a story in the local newspaper that appeared with the front-page headline "Cancer confirmed: new study underlines high risk in [community 2] area." The return of property values to previous levels comparable to southeast Edmonton began just after May 1987, when the minister convened the press conference to explain that the affair had been a mistake and about the time of our telephone survey, which explicitly reassured residents.

The chronology we had initially reconstructed from media reports and official documents did not seem to explain the apparent early fall in housing prices, which preceded the January 1987 release of the erroneous report. However, our investigative reporter learned that investigators attached to the study had held a local meeting in community 1 with civic leaders in August 1986 at which they voiced their concern over their preliminary results and implied that a serious public health hazard might be present. The timing of the drop in prices coincides with the aftermath of this meeting. Interviews with real estate agents in the area have also confirmed that they had been well aware of the cancer issue at the time

TABLE 5—Perceptions of Property Value and Residence

Survey Items/Response	Community 1, No.	Community 2, No.	Comparison Community 1, No.	P
Respondent has considered moving away				
Yes	18	29	11	< .02
No	82	71	88	
Respondent is actively pursuing selling home				
Yes	25	18	14	NS
No	65	69	74	
Not applicable	10	12 ^a	12	
Respondent believes value of property has changed				
Yes	21	39	31	NS
No	64	43	52	
Don't know	15	17	17	

Note. NS = not significant.
^a1 nonrespondent.

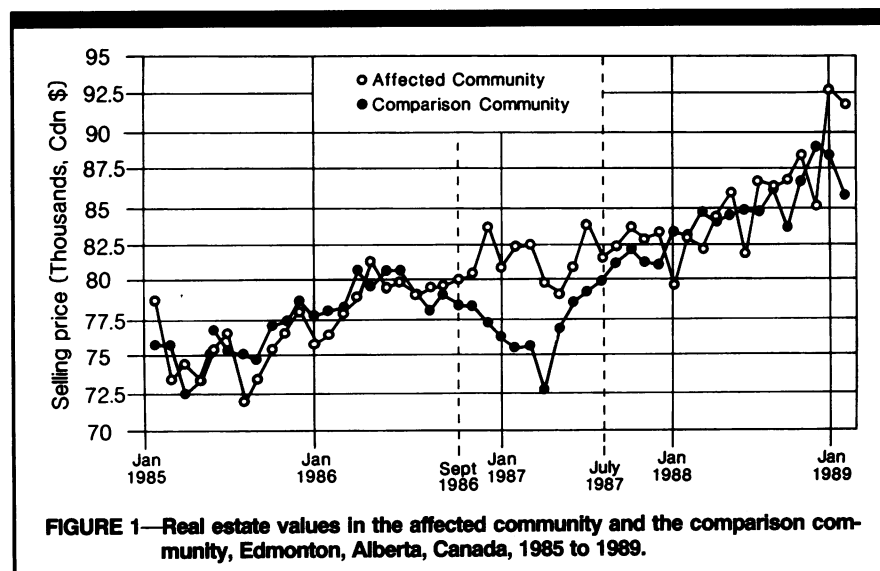


FIGURE 1—Real estate values in the affected community and the comparison community, Edmonton, Alberta, Canada, 1985 to 1989.

and had often brought it to the attention of prospective buyers.

Discussion

Surveillance of communities for evidence of environmental health risks can be a very useful strategy,³ although it can be overused, as in the familiar abuses of cluster investigation.⁴ However, this unwanted attention can have important social effects on the community.⁵ Our study documents the effects of the perception of an excess risk of cancer in a community in which the presumption was demonstrably false but that received the message from highly credible official sources.

In retrospect, it may be surprising that this incident festered as long as it did. The initial, erroneous report did not truly constitute a cancer "cluster" in the usual sense of a cluster of cases in time and space. The definition of a cluster implies cancer of the same, or at least related, type. A general, consistent pattern of elevation at many sites is not compelling evidence for an environmental cause of cancer. There were other considerations that, in retrospect, made it most unlikely that even a real (confirmed) elevation of this modest magnitude could have been associated with a significant current threat to the health of the public in either community. For example, the latency period of chemically induced cancer is typ-

ically 20 years or more, with known exceptions that do not apply to either community. This means that any conceivable exposure associated with excess cancer would have occurred around or before 1965, when the population of community 1 was only about 15 000, and well before the explosive growth of its population in the late 1970s. It would have been very unlikely for the tiny fraction of long-term residents in the area to have accounted for the entire excess cancer risk, and this should have been obvious in the age distribution. The risk profile was therefore very unlikely to have suggested a true cancer excess.

Even so, the findings were presented to the public at face value. Once released, the concern on the part of community residents led to speculation over possible causes, and the association was naturally made with the local petrochemical industry. The newspaper stories and press releases during 1986 and 1987 seemed to confirm public suspicions and reinforced the communities' concern. Whether residents of these communities have fully accepted the correction is not known, but comments made during subsequent interviews suggest that many have not. Even so, the response of real estate prices suggests that most newcomers to the community are no longer influenced by the incident.

The perception of risk seems to undermine public contentedness in a very diffuse manner. Although residents appear more often to believe that neighbors have experienced health problems, the suspected victim usually seems to be another family member or a faceless other. The residents' health-related beliefs and actions seem remarkably stable given the stress of concern, differing mainly in adoption of very general health measures. Few seemed inclined to take concrete action to move away. This pattern suggests that the local residents had formed a realistic appraisal of the risks despite alarmist publicity and that they were not overly influenced. As in all cross-sectional designs, one cannot know whether individual attitudes changed and must infer the stability of trends from frequency data.

Since housing prices are subject to supply and demand, the suggestive drop in prices in the affected community can be explained by either a lower asking price or a lower selling price. Either residents are more willing to part with their property or buyers are less willing to pay the previous market value. If the survey results accurately reflect the behavior of

residents, it would appear that buyers are less willing to pay the asking price. This might be a sign of unwillingness to move into the community; however, because sales were indeed consummated, this reluctance must be limited. It is more likely that concern over the cancer excess tipped the balance in the delicate psychology of price negotiation, adding a negative component compared with the benefit of the buyer in justifying a lower price.

The circumstances of this incident have provided a unique opportunity to assess the impact of a perceived but unreal cancer excess on the affected communities. The effect on the core health beliefs of residents appears to be negligible. An effect on health behaviors seems to be present but is not large, particularly in light of the recent changes in behavior of one of the comparison communities. An effect on residents' perceptions of health risk does seem particularly strong

for risk of cancer (already a concern), allergies, and birth defects. A strong effect appears to exist for house sales prices in the affected communities.

We conclude that a perceived elevated cancer risk may have a substantial negative impact on affected communities, both psychologically, as a result of exaggerated perceptions of health risk, and economically, as a result of depressed real estate prices. However, residents also seemed to show remarkable resistance to changes in health beliefs. □

Acknowledgments

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Tables of cancer incidence rates referred to in this paper, both factual and in error, are available from the authors. Copies of the questionnaire used in the telephone survey are also available.

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